Deciding to stay an anorectic

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Introduction

Chronic anorexia nervosa conjures up an image of a woman in her twenties or thirties who has had multiple admissions to different hospitals usually at her desperate family's insistence following a period of rapid weight loss or an overdose. She fails to gain weight in hospital, or immediately loses it after discharge which may have been precipitated by her non-cooperative or manipulative behaviour. Alternatively she or her family may sabotage the treatment programme in a much more subtle way by deceit or interference while maintaining a facade of pleasant co-operation and gratitude. It is easy to see how an atmosphere of mutual distrust builds up with each new treatment attempt. The patient and her family rapidly lose faith in the enthusiastic team who have offered help and can blame them for the treatment's failure. The professionals become disillusioned as they begin to suspect that their patient is untreatable. How can this cycle of distrust be broken so that the chronic anorectic and her family may be supported during the course of the illness, and alienation prevented? Perhaps we should abandon our so frequently unrealistic goal of a 'cure' and look towards supporting these individuals in their decision to remain anorectic, helping them to stabilize their anorexia nervosa and lead the fullest life possible with it. The problem remains of differentiating the treatable from the untreatable anorectic. This will be discussed later.

Who are the chronic anorectics?

The prevalence of chronic anorexia nervosa in the general population is unknown but almost certainly the type of patient described above represents the tip of an iceberg. These patients are well known to their general practitioners and psychiatric services and absorb a good deal of their time often with little in the way of success. The rest comprise a predominantly female group of unknown size, and its composition is based on conjecture from clinical

experience. It includes the undiagnosed who do not see themselves as ill and may be leading relatively successful lives, maintaining a low but stable body weight with amenorrhoea. Some of these are 'occupational anorectics', dancers, models and athletes, where the condition fits their life style and may remit when such work is discontinued. It includes a proportion of middle-aged women who, after an episode of anorexia in their teens, may have maintained their weight sufficiently in adulthood to conceive their offspring but slip back into marginal anorexia at the time of the menopause. Another group are recognized by friends and family as anorectic but refuse to seek or to accept treatment although they may realize they have a problem. Unfortunately the final group is largely iatrogenic. What might be a transient episode of anorexia in adolescence, with adequate treatment at an early stage or spontaneous recovery, may develop into chronic illness as a result of treatment during which restoration of normal eating patterns is disregarded in favour of rapid weight gain. Anorectics and their families may be deterred from seeking further help after such procedures as nasogastric feeding or insensitive behavioural regimes particularly when no attempt is made to change the psychodynamic factors precipitating or maintaining the illness.

The development of chronicity

Epidemiological studies in Sweden and Britain in the early 1970s suggested prevalence rates of an anorexia nervosa syndrome of between 1 and 10% for adolescent females, and 0.05 and 0.1% for males (Nylander, 1971; Crisp, Palmer and Kalucy, 1976). All the evidence suggests that anorexia nervosa is becoming more common, particularly in its bulimic form. Dieting behaviour amongst adolescents is now the norm in western countries, encouraged by the fashion for slimness, peer pressure and the media. A recent survey of a New York university population identified 19% of female students and 5% of males

with intermittent bulimia as outlined in the DSM-III*, and 10% of the total population exhibited weight control by self-induced vomiting or purgation (Halmi, Falk and Schwartz, 1981). Because of recent publicity given to the condition those affected are recognized more frequently and it is likely that the growing group of chronic anorexics in the population will begin to seek help in ever-increasing numbers. Specialist departments are already swamped with referrals and their management will increasingly fall back on general practitioners, gynaecologists and others. The clinical task is to differentiate those who are likely to respond to treatment from those who may be helped most by a process of working towards a decision to live with anorexia nervosa and subsequent support. This decision may only be reached by attempting treatment but a detailed clinical interview of the anorectic and her family may identify those for whom life with their illness is the best option. The most important factor is the stage of the illness, and this must be seen in the context of the natural history of anorexia nervosa. Approximately 40% recover spontaneously from an episode during adolescence. A further 20% respond to treatment leaving 40% of cases with chronic anorexia which has a variable course and clinical picture (Hsu, 1980). Some have several episodes in their teens or twenties with or without full recovery between relapses. A proportion of these may respond to treatment. Bulimia, with or without vomiting, may be present from the outset or may develop at any stage of the illness. Once chronic the illness may remain very stable over a lifetime or it may be unstable. Instability is associated with multiple treatment failures and a deteriorating degree of adjustment, in contrast to the stable form which may lead to a relatively good adjustment in the absence of treatment.

Morgan and Russell (1975) and Hsu, Crisp and Harding (1979) identified factors associated with poor prognosis. Duration of illness itself predicts poor outcome and thus so will factors associated with chronicity such as previous psychiatric treatment, bulimia and vomiting. Other factors help to distinguish those patients who may respond to treatment from those who are unlikely to do well. These include low body weight at presentation, older age at onset, lower social class, marriage, poor premorbid personality, difficulties in childhood, disturbed relationship with family and parental marital problems. However, motivation is of overriding importance. Because of the strong unconscious need to remain anorectic in spite of a conscious determination to recover, decisions about intensive treatment versus supportive

management often cannot be made at presentation. A longer evaluation of individual factors sustaining the anorexia is required and may only be obvious if an attempt is made to treat the individual. The clinical features and severity vary enormously but the following examples illustrate the quality of life which can be expected with the condition.

Life as an abstainer

The chronic abstainer frequently does not seek help but when she does she may be hoping to relieve her preoccupation with food or her depression, rather than to gain any weight. She may tacitly co-operate with the goal of weight gain as her ticket into treatment. After several years of anorexia nervosa her desire for low weight is by now conscious. She is aware of the battle between her rational self which would like to be 'normal' and her irrational fearful self which clings to anorexia. The distortion of body image has lessened and she is likely to admit she is too thin, although terrified of gaining even a kilogram or two. She has become more aware of unpleasant feelings, panic, anxiety or depression associated with weight gain and is less preoccupied with bodily sensations of feeling fat or bloated. A 29-year-old secretary, recovering from a serious relapse with out-patient treatment, firmly refused to go above seven stone (44.4 kg). Her marriage and sexual relationship had improved and her eating pattern was fairly normal but she said 'I remember how depressed I was when I was eight and a half stone (54 kg). I never want to go through that again.' She had made a conscious decision to remain anorectic. It made it possible for her to remain at home rather than to work and she could avoid all social contact except with her husband.

The severity of anorexia with respect to body weight does not reflect the determination with which it is clung to, and it may be easier to treat someone who is severely under weight than to dislodge a woman who rigidly maintains her amenorrhoea at a weight just below her physiological weight. She feels in control and attractive at this weight and is not prepared to take the risk of discovering whether life would be any different a few kilograms heavier. She fears she will lose everything, but especially her ability to remain anorectic. Most stable chronic abstainers control their weight precisely and can, in spite of their fears, reverse any recovery which threatens to begin. The recovered anorectic may describe a mourning process for her anorectic self, for an identity and a way of life which has been hers for so long.

What is this life which she will miss? It is a life dominated by food both night and day. Frequently a rigid precise eating pattern is adhered to as the

* *The Diagnostic and Statistical Manual of Mental Disorders*, American Psychiatric Association, 1980.

anorectic gradually discovers she has more control when she eats a regular diet which includes carbohydrate. Weight control is by diet and exercise alone and she is often proud of her wholesome diet, rich in bran, vegetables and fruit. She helps to boost the market for health foods, health and slimming magazines, and for recipe books. Although she argues that meat, fat or sugar in her diet are unhealthy, she may remain eager to provide these foods for her family. She sleeps for only four or five hours at night and much of her time, not spent asleep or at work, may be devoted to exercise, particularly walking or swimming. She is conscientious in the extreme, working long, meticulously and reliably, satisfying most employers. In the home she is excessively houseproud which may make life difficult for her family. She is upset when her routine is disturbed and her activities may become increasingly restricted and isolated. She is a solitary individual even when superficially socially competent. Her personality is bland and compliant, with a strong stubborn streak when her control system is threatened. She shows marked denial and is out of touch with her feelings. Although she may form or remain in close dependent relationships, her capacity for mature relationships, particularly with men, is limited and her sexuality is undeveloped. Her narrow life style is so rigidly maintained that a whole socialization process has to be developed if she recovers. Life is barren with anorexia but it becomes even more barren and painful without it.

Life as a bulimic

The chronic bulimic is very different from her abstaining counterpart and she finds life much less tolerable. She is much more in touch with her feelings, and feels out of control in both her behaviour and her emotions. She binges to relieve overwhelming feelings of non-specific tension, anxiety or depression. After consuming an extraordinary amount of carbohydrate food she is physically uncomfortable and disgusted with herself. Emotional relief comes with vomiting or purgation, but she experiences a constant fear of discovery and a persisting sense of shame. The disorder, while secret, is relatively socially adaptive and the bulimic may keep this secret for many years, even from her spouse or family, particularly as she is more likely to be at, or close to, average weight. She is tormented with guilt and her fears of discovery and resultant rejection perpetuate chronicity. She is less socially isolated than the abstainer but usually reports inconsistent and unsatisfactory relationships. Although a Canadian study found two thirds had engaged in a sexual relationship and half used oral contraceptives, only 6% reported frequent sexual relationships (Garfinkel,

Moldofsky and Garner, 1980). The bulimic is not promiscuous but tends to engage in sex readily within a new relationship which tends to break down as her voracious dependency needs are awakened. Only a relatively small sub-group of severely disturbed chronic bulimics engage in impulsive behaviour such as drug or alcohol abuse, self-mutilation or suicidal attempts, but stealing is common. She may steal money because of financial difficulties resulting from enormous sums spent on food, but more usually she steals food from shops, family, colleagues and may scavenge in waste bins. In some households locks are put on refrigerators and store cupboards. Finally, an arrest for shoplifting draws attention to her plight and may precipitate a request for help. In contrast, the 'well controlled' bulimic frequently organizes her life around her bulimia and her binges may only occur when alone late at night. Frequently she abstains during the day or even for a few days at a time and tends to be active, outgoing and cheerful during this period, withdrawing socially when she binges. As chronicity sets in and life becomes more settled she may plan binges either alone or in social situations. 'I know I can't control myself at a buffet so I just get on with it as soon as I arrive. Anyway I can't bear not to taste everything.' This woman, who abstained between binges, gradually became aware how her binges protected her from her underlying fears and disappointments in social relationships as she began to eat regularly and her bulimia waned. Her facade of confidence had convinced even herself. Bulimic episodes may become institutionalized, particularly with married patients, who can indulge in gourmet restaurants or at dinner parties, sustaining an otherwise empty but mutually dependent relationship with their spouse. These relatively stable bulimics no longer struggle to stop themselves bingeing but they share with other bulimics a terror of the weight gain which will occur if they discontinue vomiting or purging. Few realize that the 5 kg or so which can appear overnight is largely secondary to rehydration and fluid retention. Any weight change tends to show in her face which may attract comments and she finds this more difficult to bear than the fear of longer term complications, even if they affect appearance such as damaged tooth enamel. It seems that the pre-existing weight phobia is reinforced by the large and rapid fluctuations in weight which most bulimics experience unless they maintain a state of permanent dehydration with laxatives, diuretics or self-induced vomiting.

Life as a middle-aged invalid

With increasing awareness of anorexia nervosa by the medical profession, another older group of chronic anorectics is being identified. Some middle-

aged or elderly women have had anorexia since adolescence, unknown to themselves or others. Others, after a transient episode in their teens, again lose weight at the time of the menopause as their children become independent or their parents die. A proportion are chronic invalids or hypochondriacs, often looked after by a spouse who remains locked in a sterile marriage. This group may be chronic attenders of medical or surgical out-patients but rarely of psychiatric clinics. They have multiple physical complaints, thick files, and may undergo repeated investigations and operations for backache, abdominal pain, gynaecological disturbances and weight loss. Presenting a depressed picture, they tend to idealize their pre-morbid selves as active, outgoing, healthy and happy. They comply willingly with unpleasant investigations and long admissions and only become anxious when their failure to gain weight is questioned or when they fear that their doctors suspects their illness may have an emotional basis. They consume a considerable amount of medical resources and may have unnecessary operations. Perhaps a proportion of oesophageal symptoms and bowel problems may be the result of years of vomiting and laxative abuse but confirmation of this would be difficult to obtain. Denial is so great in these patients that treatment of their eating disorder is almost always impossible.

Another group of chronic anorectics are recognized when their daughters develop anorexia. Their own anorexia, usually stable and mild, is completely denied although some will admit in private that they had an episode of weight loss in adolescence. Their denial protects against overwhelming guilt because of the role their own preoccupation with food, appearance and control has played in their daughter's illness. Confronting such a mother with her illness only serves to alienate her and may be destructive to her daughter's treatment. Preferably, she should be helped to disentangle herself from her daughter's eating difficulties and encouraged to establish new ways of relating to her daughter, and, importantly, to her husband. The father of one anorectic realized only after his daughter has been treated for 2 years that his own mother had been anorectic. He remembered how she never ate a meal with her family although she loved cooking. She was proud of her tiny waist and seemed unaware of her wasted limbs. When her children married and left home she succumbed to cancer. He said 'It was a blessing. It was the only way she could have left my father and without us she had no reason to live.'

Living with a chronic anorectic

Family life with an anorectic may be intolerable. However, some families find it easier to live with the

anorectic than to allow her to recover, and indeed some men choose to marry anorectics. Recovery may produce change which a rigid, enmeshed family is ill equipped to handle. Parents face problems within their own relationship when their daughter leaves or a husband may be unable to tolerate his exposed dependency needs when his wife becomes independent and emotionally expressive. However, these dynamics remain concealed by the anorexia which may dominate the family relationships and life style. Usually the mother is preoccupied with her daughter's diet and health and may coax her to eat for years. Family rows, when they occur, tend to be about food and indeed conflict may only be expressed through the anorectic. She remains over-protected and continues in a childlike role in her family for many years. The chronic abstainer becomes easier to live with as time goes on. As the family begins to feel more confident that she will survive they relax and stop trying to help. Her mother no longer gets upset when she does not eat with the family and her social isolation, coupled with a good work record, is acceptable.

The bulimic is less acceptable to her family. Her unpredictable binges mean that no food is safe. The family are aware of her rapid disappearance after meals, and the evidence of vomiting and laxative abuse is hard to conceal. In addition, there may be much more open conflict with tears, anger, and suicide threats on the one hand, and crises such as arrests for shoplifting, overdoses, or alcohol abuse on the other. The family do not know whether to regard her as sick or bad. Usually they treat her with concern, but she will sense their covert hostility. Those anorectics who have more severely disordered personalities have more overtly rejecting or indifferent families who have been driven to distraction over the years. Patience or complacency runs out sooner for the families of bulimics than abstainers but the most important factors are the stability of the illness, physical complications and the degree to which the illness is manifest. Sometimes the most chronic illness occurs in married women who seem otherwise well adjusted and keep their secret from their husbands. The fact that it can remain a secret gives some clue about the marital relationship which is put under strain when the anorexia is brought out into the open.

The decision-making process

The decision to support a chronic anorectic rather than to treat her should not be undertaken lightly and need rarely be regarded as a permanent decision except for the middle-aged (Crisp, 1980). More often than not the patient is unwilling or unable to give up her anorexia at the time of consultation or admission. It is more helpful to discuss with her the major task

she faces in overcoming her fear of weight gain and to bring out into the open her terror of the future, than to leave her feeling that she has failed and has been rejected because of her lack of co-operation. The door should be left open for further treatment whenever possible.

How is the decision arrived at? This depends on the stage, and the course of the illness, as well as the motivation of the patient and her family to change. The advantages and disadvantages of the illness for the individual may not be immediately apparent but can be explored through an extended assessment or treatment trial. The questions which should be answered are, 'Is this person likely to be better off without anorexia in the long-term?' and, 'Has this person got the resources, both internal and external, to cope with the process of recovery?'

The first consideration is the stage of the illness. The adolescent should always be treated aggressively even if she has made a decision to remain anorectic. The results of family therapy, with or without admission, for adolescents with a short history are good (Rosman *et al.*, 1977) and, although systematic follow-up studies are not yet available, preliminary findings suggest that brief out-patient family therapy may improve overall adjustment and increase motivation to change or accept intensive treatment in the long-term (Hall and Crisp, 1981). In contrast, the middle-aged anorectic is rarely treatable unless she is highly motivated and long-term psychotherapy is available for the major reconstructive work necessary after weight is restored. Excluding these two groups, the remainder, in their twenties or early thirties, need to be considered carefully.

The course of the illness is crucial. If the patient is likely to die, suffer permanent physical damage or is a serious suicide risk, a major effort should be made to treat her intensively. Unfortunately compulsory treatment is only of value as a life saving measure, and all efforts should be made to help the patient to accept treatment voluntarily. In general, an unstable course with remissions, relapses and crises is likely to lead to greater motivation on the part of the patient and her family, particularly as it indicates change is already occurring. A history of multiple treatment failures may reduce motivation. A stable pattern with a relatively successful adaptation to the anorectic life style suggests that treatment may be unsuccessful unless change occurs to precipitate instability. Bulimia overall carries a worse prognosis than the abstaining form, but it shows considerable heterogeneity, and many professionals are now gaining experience in its treatment. In particular, out-patient cognitive therapy shows promise, at least for bulimics within 15% of average weight (Fairburn, 1981). Clinical observation suggests that the eating disorder in these cases may be more habitual and physiologi-

cal in nature, arising from periods of abstinence and carbohydrate deprivation. Overall adjustment may be satisfactory in contrast to those bulimics, referred to specialist departments, who have low body weight, underlying personality disorders, profound weight phobia and have experienced multiple treatment failures. The latter respond poorly to other than intensive in-patient treatment coupled with long-term psychotherapy, although desperate for help. Treatment should be attempted with this group because of the long-term physical and emotional disability and high suicide risk. The goal may not be recovery, but limited clinical improvement may considerably enhance the quality of life for the patient and her family.

Assessment of motivation or potential motivation can be difficult and may only be possible by a treatment trial. The decision to remain anorectic may have already been made unconsciously by an individual who professes a strong desire for recovery. Similarly, a family energetically pursuing treatment for their daughter may be unaware of their need to have a sick family member. Overcoming resistance and making these constraints conscious may indeed be therapeutic, especially if the guilt so exposed is dealt with sensitively. When the internal conflict is brought into the open the anorectic feels that at last someone understands the strength with which she is held in her anorexia and that it is beyond her control, while her conscious wish for recovery is acknowledged and can be reinforced. Presenting her with the choice whether to recover or not gives her some self determination, particularly as she begins to understand the personal advantages and disadvantages of remaining anorectic. The disadvantages of remaining anorectic are usually obvious but the long-term outlook should be explained fully.

What are the advantages of anorexia nervosa? The abstainer is protected from unpleasant feelings such as anxiety and depression and her family, who find these emotions hard to bear, is similarly protected. She feels in control and socially acceptable, supported by the pressures to be slim in present-day society. The pre-pubertal psychological stance avoids development of sexuality and the difficulty of establishing mature relationships. Separation from the family may not occur and when the anorectic moves away she remains over-involved. The family is protected from change. A father may continue to opt out while his wife remains tied to his daughter, a barren marriage may be sustained, or a mother may avoid her own depression while she has a sick daughter to look after. A 32-year-old woman with an 11-year unconsummated marriage described the advantages to her longstanding anorexia: 'I feel superior when I refuse fattening foods at parties, especially when I see others tucking in. I am proud of

my strong will-power. I still get a lovely feeling when someone compliments me on being slim. I'm still very afraid of being overweight again, and I enjoy wearing small sizes in clothes even though I know if I were at target weight I wouldn't be a size 16. This is not really a conscious thought, but having no periods makes me feel "safe" from becoming pregnant. Although I don't feel unattractive, I feel disinterested in sex and I don't attract other men, which stops me from becoming dissatisfied with my husband who is unable to achieve intercourse.' She had decided to remain anorectic after intensive out-patient treatment including sexual therapy, because it provided the safest solution for her.

The advantages of bulimia are less obvious but the bulimic episodes protect her against overwhelming emotions, particularly underlying anger, which are more threatening to the individual and her family than the disgust and guilt which she comes to tolerate. Some individuals, who would otherwise be obese, are able to maintain a normal weight, and bulimia offers the same protection against anxiety and depression which obesity confers (Crisp, 1977). The individual can indulge in the pleasures of eating without paying the price in weight gain and loss of social acceptability. The price she pays for treatment is loss of secrecy and the pain of facing up to her self destructiveness. The advantage for the family is that it may be more acceptable for them to regard their daughter as ill than to face the challenge to the family value system which recovery produces, particularly in terms of sexuality, expression of anger or unacceptable opinions. The family may have to deal with an issue which could remain buried with the anorexia. The father of a 21-year-old male bulimic undergoing treatment was finally able to mourn the double suicide of his parents when he was aged 13, the age at which his son became ill and their previously good relationship disintegrated.

It may be impossible to determine with any degree of certainty the specific psychodynamic issues which are avoided by remaining ill, but informed guesses may be valuable to the patient even when they are met with denial. For example, it may be preferable to help an anorectic who will be unable to separate from her parents to develop her life while remaining at home, than to reinforce her denial and attempt to separate her from her parents with the risk of deterioration in her condition. A chronic anorectic may be affected adversely by treatment in a way which could not be predicted at the outset, for example, the precipitation of a psychotic illness or suicidal depression. More frequently the anorectic, after years of illness, is left with overwhelming depression or unbearable emptiness after weight is restored. Life for these patients would have been better with the illness.

Reversing the decision

Having decided to remain anorectic, the individual should be warned that the time may come when her stable situation breaks down, precipitating a relapse or depression. The possible provoking factors can be predicted or anticipated with the anorectic in advance, such as the death of a parent, marital breakdown, arrest for shoplifting, redundancy or merely encroaching age. Anorectics are at risk from suicide as they reach their thirties, when they become increasingly depressed as they lose their denial mechanisms and anorexia nervosa ceases to provide it advantages. Chronic anorectics may request treatment after many years of illness but treatment is a difficult and complex process and should not be undertaken lightly as the following example serves. After 3 years of intensive psychotherapy and a 6 month admission a 41-year-old woman who had been ill for 20 years writes 'I am quite a changed person in many respects. Achievement of my target weight was like completely transplanting one person for another. I had to almost destroy what was there to discover what was there all the time. It simply needed the proper nourishment, under proper conditions. I still have much of my anorexia: frantic physical activity, imbalance of eating with living, basic insecurity, a feeling of being "stuck", obsessive patterns and habits with a fear of changing them, a basic fear of the unknown, and a fear of commitments especially to relationships. I wonder if I am really a woman and whether I want to be one. Perhaps I would rather be a man. I am still unaware of my potential and not yet emotionally ready for a full-time job. I fear being too positive for fear that it may disappear. Is it real that I am getting better? Yet I am becoming stronger and more aware of myself, more prepared to take risks. I even get twinges of what it may feel like to be "normal"'. This kind of change is only likely to occur if the personality is well preserved and some social relationships maintained, but it depends on the psychotherapeutic resources of the treatment team.

Long-term management

How can the medical profession help the ever-growing number of chronic anorectics in the population? Some may never be diagnosed and that may be most helpful of all. Others will appear in the general practitioner's surgery, gynaecological, medical or psychiatric out-patient clinics. For some of the older patients confrontation with a diagnosis of anorexia may serve no purpose and support should be provided for their families with careful management by one department to avoid unnecessary admissions or investigations. For younger patients information

about their illness and its present risks and future prospects is invaluable even if it is not met with denial. The advantages and disadvantages of treatment should be discussed. If a recommendation is made by the specialist that the anorectic live with her condition, at least one further appointment should be made because sometimes a searching assessment interview may destabilize the anorexia. A review in 6 to 12 months' time with management advice is likely to be helpful to the general practitioner who will increasingly accumulate these patients on their lists. They will become experienced in supporting these patients as they are with chronic hypochondriacs or neurotic patients. Practical measures such as dietary advice to improve eating patterns and carbohydrate intake, reduction of laxative abuse and vomiting, with encouragement towards limited weight gain and frank discussion with suggested reading material for the individual and her family should make life more comfortable for all. The goal of management should be achievement of stability of below the critical weight of approximately 47 kg when the protection anorexia affords is lost. With a good therapeutic relationship established the path will be paved for treatment at a later stage if it becomes indicated. Meanwhile the limited specialist resources can be devoted to one-off consultations and the intensive treatment of those at an early stage of the illness or those chronic anorectics for whom anorexia is no longer a solution.

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